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1.0 Background

This document articulates SickKids' guidelines and procedure for the management of patients and families who are Jehovah's Witnesses, with respect to blood and blood products.

Jehovah's Witness scripture and teachings preclude transfusion of whole blood or its major components. These texts regard donor-derived blood transfusion (whole blood, red cells, white cells, platelets and plasma) as contrary to scriptural commands. Many Jehovah's Witnesses therefore request medical management using alternatives to blood transfusion, e.g. blood conservation and 'bloodless' surgery (i.e. surgery performed without the use of transfused blood) or, where blood transfusion is the only option, refuse transfusion altogether. It is important to understand that the vast majority of Jehovah's Witnesses perceive blood transfusion as an assault; each additional amount of blood transfused and each additional transfusion is seen as an additional assault, i.e. it is not the case that after blood has been given once 'the damage has been done'.

Jehovah's Witnesses do not absolutely prohibit the use of some blood fractions that may have been processed or derived from plasma or blood cells (e.g. albumin, clotting factors, immune globulins, fibrin glue, cryoprecipitate, oxygen-carrying red-cell substitutes, interferons). Typically, Jehovah's Witnesses will refuse consent to whole blood products for themselves and their children. However, since Jehovah's Witness patients and families make their own individual personal decisions on these matters it is important to discuss the acceptability or otherwise of transfusion of blood and specific blood products with each individual patient and/or substitute decision maker(s) (SDM)¹.

Currently, the transfusion of whole blood, its major components and blood-derived products require informed consent (as with any other treatment). In accordance with SickKids' <u>Consent to Treatment policy</u> (Section 3.9) and the *Health Care Consent* Act (*HCCA*), no informed consent is required if there is an emergency, no SDM is available or willing to provide consent, and the previously stated wishes of the patient while capable and when aged 16 years and older are not known.

As is the case with all children, in non-emergency situations, if a patient is incapable of making decisions about a treatment (including blood/blood products) and their SDM(s) do not consent to treatment believed by the health care professional(s) involved to be in the child's best interests, this may engage a duty to report to the Children's Aid Society (CAS) or Consent and Capacity Board (CCB) (see <u>Consent to Treatment policy</u>).

History of Care of Jehovah's Witness Patients and Families at SickKids

On February 1, 1999 the Chief Coroner of Ontario recommended that all Ontario hospitals develop a policy and procedure related to the management of patients and families who are Jehovah's Witnesses. The Coroner noted the need to ensure the following:

¹ (Note: In the majority of cases, if a paediatric patient is incapable of making decisions with respect to a treatment, their parent(s) are their authorized substitute decision maker(s) (SDM(s)). Use of the term SDM(s) in this guideline acknowledges that parents may not be the authorized SDMs in all cases. There may be cases where another individual or individuals are the patient's authorized SDM(s); for example, the patient's grandparent(s) or a Children's Aid Society (CAS) representative.)

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- That health care professionals be respectful of the requests of Jehovah's Witnesses, even though they may not necessarily act in accordance with these requests.
- That health care professionals have and document a discussion about alternative treatment options with Jehovah's Witnesses (such as microsampling and available non-blood product treatment therapies).

The Letter of Understanding

A SickKids Letter of Understanding was jointly created in the 1990s by representatives from the Jehovah's Witness Hospital Liaison Committee, representatives from the SickKids Departments of Bioethics, Quality and Risk, and Legal, front line clinicians (including surgeons, anaesthetists, haematologists, neonatologists, and emergency department physicians), and organizational leadership. The letter is not a consent form and, as with all treatment, informed consent to the use of blood/blood products should still be sought from patients (if capable of making this decision) and SDM(s) (if patient incapable of making this decision).

The Letter of Understanding guides a conversation with the SDM(s) regarding the care of a patient who is incapable of making decisions regarding blood/blood products.

2.0 Guiding Principles for a Care Plan with Jehovah's Witness Patients and SDM(s)

The guidelines are based on the following guiding principles:

a. The best interests (as defined in the HCCA, Section 21) and well being of all paediatric patients are paramount;

b. Patients capable of deciding with respect to a proposed treatment shall make their own decision, should they wish to do so;

c. Where there is a conflict between health care practitioners and patients and/or SDM(s), the health care practitioner shall take all reasonable steps to resolve such conflict as cooperatively as possible and to respect the integrity of the family unit (see <u>Guideline for Addressing Value-Laden Conflicts Between Patients and/or Substitute Decision Makers and Health Care Professionals</u>);

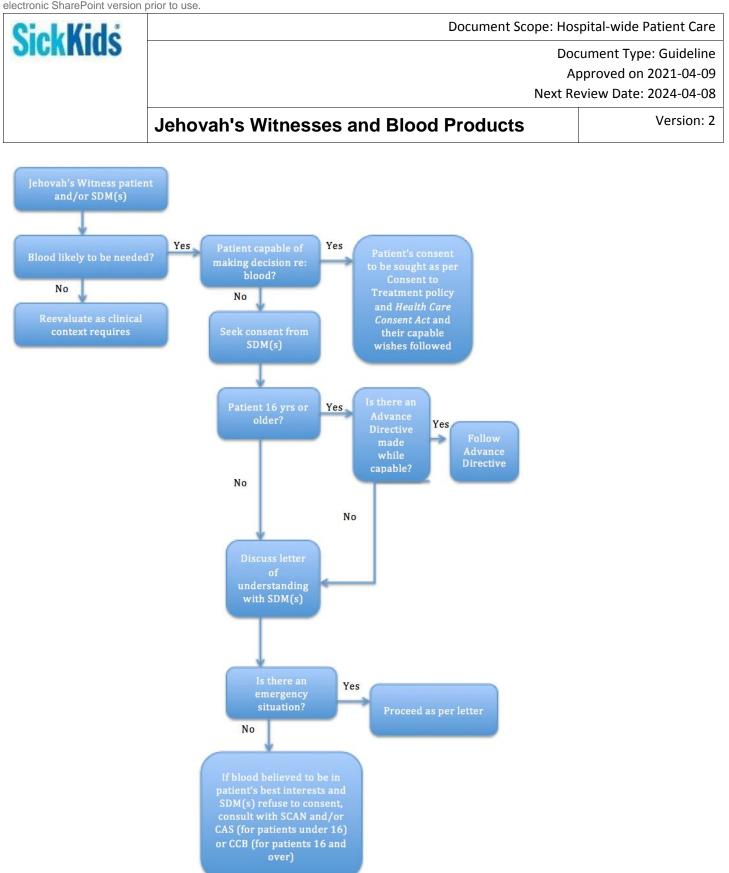
d. Confidentiality of health information shall be respected, within the limits of the law;

e. Patients and their SDM(s) shall be treated with respect and dignity;

f. Care of Jehovah's Witnesses patients, and interactions with SDM(s), shall be governed by a commitment to take reasonable steps to avoid the use of blood and blood products in the care of the patient, as described in Section 3.3.1 below;

g. Patients and SDM(s) shall be informed and supported throughout this process, and information shall be provided to patients in a developmentally appropriate manner.

The following flowchart outlines the steps and procedures referred to in the Guidelines below:



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3.0 Guidelines

When a health care professional(s) believes that a Jehovah's Witness patient requires blood or blood products, a conversation with the patient and/or SDM(s) should be held to determine their wishes regarding use of blood/blood products.

3.1 The Necessity of Using Blood

It is important to evaluate whether blood/blood products are the only treatment option, and if all other treatment methods have been considered. The Blood Conservation and Autologous Clinic can provide information (ext. 206264) and in emergencies the Haematologist on call should be contacted, time permitting. Members of the Jehovah's Witness Hospital Liaison Committee have access to extensive information on alternatives to blood transfusion (see Section 3.6 below) and can be contacted for assistance. Liaison representatives assigned to The Hospital for Sick Children may be reached by pager at 416-441-6460. Patient confidentiality **must** be respected and the names of the patient and SDM(s) should not be mentioned.

Early consultation is encouraged if the patient, SDM(s) or the health care professional(s) involved have questions or concerns. Some possible resources include <u>Guideline for Addressing Value-Laden Conflicts Between Patients and/or</u> <u>Substitute Decision Makers and Health Care Professionals</u>, <u>Guideline for Bioethics Consultation</u>, Bioethics Department (ext 205000), Quality and Risk Management (ext 207358), the Blood Conservation and Autologous Clinics (ext 206264), the haematologist on call and the Child Health Services (CHS) Administrator on call.

3.2 Patients with Decision-Making Capacity Regarding the use of Blood/Blood Products

The Responsible Physician must make the determination of the patient's capacity (as in all treatment decisions) to decide regarding blood/blood products (for more information, see the <u>Consent to Treatment policy</u>). Psychiatry may be consulted for assistance if the patient's capacity to decide regarding blood/blood products is uncertain.

If the patient is deemed capable of making medical decisions related to the use of blood/blood products, they have the authority to give or refuse to give consent. A valid decision must be fully informed and voluntary. It may be a challenge to determine the independence of patients' decisions in these circumstances. As with all patients, the decision making of Jehovah's Witness patients may be influenced by others (e.g. family members, friends, religious advisors). Assess the independence of the patient's decision, if possible, by speaking with the patient alone, and/or by involving an appropriate member of the interprofessional team, such as a social worker.

If appropriate treatment methods that do not require blood/blood products are available, and that is what the patient is requesting, treat the patient without the use of blood/blood products. If the only medically appropriate methods available involve the use of blood/blood products and a patient who is capable of making this decision refuses these methods but wishes to undergo the procedure (e.g. surgery), the Responsible Physician, after appropriate consultation, will need to decide if they are willing to perform the procedure without blood/blood products.

When a patient is deemed capable of deciding about blood/blood products, and expresses a wish not to receive blood transfusions or blood products, this should be documented in the patient's chart and should be communicated amongst members of the treating team in the circle of care. These wishes should also be followed if the patient is over 16 and later becomes incapable of deciding about blood products, and/or is transferred to another unit within the hospital. While there

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is no age of consent to treatment, the age of 16 is relevant for the use of advance directives, as per the <u>Consent to</u> <u>Treatment policy</u> and Section 21 of the *HCCA*.

3.3 Patients Without Capacity to Decide About Blood/Blood Products

3.3.1 When blood transfusion is likely to be needed and the patient is incapable of deciding about blood/blood products and under the age of 16

When a Jehovah's Witness patient has a medical condition and proposed treatment may require blood transfusion and the patient is incapable of deciding about blood/blood products, the Responsible Physician should meet with the SDM(s), inform them of the circumstances and seek the SDM(s)' consent to use blood/blood products.

Letter of Understanding

If the SDM(s) refuse to provide consent and the patient's medical condition and/or treatment is one in which blood transfusion may be required imminently or urgently, the Responsible Physician should review the <u>Letter of Understanding</u> for Jehovah's Witness Patients and Blood Transfusion with the SDM(s) and offer them the opportunity to sign the Letter as an indication of acknowledgment.

The Letter of Understanding should be used in circumstances where Jehovah's Witness SDM(s) refuse to consent to blood transfusion for a patient who is incapable of making decisions with respect to blood/blood products. When a physician signs this letter, they are making a commitment to do whatever is reasonably necessary to avoid the use of blood/blood products in the care of the patient. When SDM(s) sign the letter, they are acknowledging the physician's legal duty to treat the patient with blood if necessary, in the case of an emergency (see Section 3.4 below). This acknowledgement means that it is not necessary to contact the Children's Aid Society (CAS) if blood must be administered in these emergency situations.

Notes:

- The Letter of Understanding is not a consent form, and SDM(s) who sign this letter are not consenting to blood for the patient.
- This guideline is linked to the only authorized version of the Letter of Understanding for use at SickKids.

3.3.2 If SDMs disagree with each other

Unless there is legal documentation giving one parent full custody and health care decision-making authority, parents are equally ranked SDMs and parental consensus is required before a decision can be made. See the <u>Consent to Treatment</u> policy (Section 3.7.4) regarding how to proceed in situations where equally ranked SDMs disagree with each other. In these situations, consultation with Risk Management is encouraged.

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3.4 In Emergency Situations

In an emergency situation, as defined in SickKids' <u>Consent to Treatment policy</u> and the *HCCA*, patients who are not capable of making decisions with respect to a proposed treatment may be treated without obtaining informed consent if "the delay required to obtain a consent or refusal on the person's behalf will prolong the suffering that the person is apparently experiencing or will put the person at risk of sustaining serious bodily harm". An exception to this is if the patient, while capable and over the age of 16, has previously expressed a wish applicable to the circumstances to refuse consent to blood/blood products (see next section).

If and when emergency transfusions are provided, ensure that the reasons for the necessity of transfusion are well documented.

3.5 Advance Directives

Many Jehovah's Witnesses who are adolescents aged 16 or over will have completed a card that indicates that they will not accept blood products. Under the *HCCA* (1996), SDMs must make decisions according to the wishes expressed in such directives under the following circumstances:

- The patient presently lacks capacity to decide with respect to blood/blood products (due to illness, injury, etc.) and
- The patient completed the card/directive when 16 years or older (while there is no age of consent to treatment, one must be at least 16 to complete an advance directive) **and**
- There is no reason to believe that the patient was incapable of making decisions with respect to the proposed treatment when they completed the card/directive **and**
- There is no reason to believe that it was completed involuntarily.

See Section 21(1) (Principles for giving or refusing consent) and Section 26 (No treatment contrary to wishes) of the <u>HCCA (1996)</u>.

3.6 Jehovah's Witness Hospital Liaison Committee

This is a committee of Jehovah's Witnesses, and not a hospital committee. Members of this committee are available to provide support and information - they should only be contacted in regard to a specific case at the request of and/or with the consent of the patient or SDM(s). They may also be consulted by SickKids staff for general information, i.e. without divulging the identity of or details about a specific patient and/or SDM(s). Liaison representatives assigned to The Hospital for Sick Children may be reached by pager at 416-441-6460.

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3.7 Confidentiality

As with all patients, confidentiality about decisions made and treatment provided should be strictly preserved within the limits of the law. Patients and SDMs have the right to control if and how information is shared with others beyond the immediate responsible treatment team. The need for internal consultation, legal consultation, and/or mandatory reporting to a CAS are lawful exceptions. SDM(s) may wish to delay disclosure to the patient that blood has been given until the crisis has passed.

3.8 If Blood is Given

The patient's (and/or SDM(s)) need for counseling should be assessed/determined.

Staff may experience moral distress when they are required to give blood contrary to the wishes of SDM(s), or when a patient's refusal is honoured. Debriefing sessions may be helpful in these circumstances. The Bioethics Department may be contacted if assistance is desired with group or individual debriefing regarding the ethical considerations.

4.0 Conscientious Objection

Sometimes patients' or SDM(s)' wishes conflict with health care professionals' personal values and beliefs. In such cases, health care professionals have a right to conscientious objection; that is, they may withdraw from the care of the patient. However, as stated by most professional codes of ethics (e.g. the College of Physicians and Surgeons of Ontario Policy on '<u>Professional Obligations and Human Rights</u>'), health care professionals may withdraw from the care of a patient only after making an effective referral to another appropriate treatment provider(s).

5.0 Documentation

All discussions and decisions should be fully documented in the health record. This will let other members of the health care team know what steps have been taken. If the Letter of Understanding is used, it should be placed at the front of the patient's chart.

6.0 Related Documents

Canadian Medical Association Code of Ethics

College of Nurses of Ontario Practice Standard - Ethics

College of Physicians and Surgeons of Ontario Policy 'Professional Obligations and Human Rights'

Consent to Treatment Policy

Guideline for Addressing Value-Laden Conflicts Between Patients and/or Substitute Decision Makers and Health Care Professionals

Health Care Consent Act (1996)



Attachments:

JW Letter of Understanding (002).pdf